# ANNUAL REPORT 2023

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL/EN

# COLOPHON

This is a publication of CMTC-OVM
All rights reserved.

**Chairman and author**
Lex van der Heijden

**Owner**
The board of Vereniging CMTC-OVM

**Treasurer**
Alexandra Haan

**Secretary**
Anja Fluijt

**Board member**
Laurens Rorive

**Graphic design**
Rick Schurink, Design Delicious

@CMTC

facebook.com/cmtcovm

Linkedin cmtc-ovm

CMTC-OVM

Instagram.com/cmtcovm

www.cmtc.nl/en/en

The patient association was
formally established on 22 January, 1997

# CONTENTS

# 1 INTRODUCTION

**1.1 Purpose of this Document**

This document contains the 2023 annual report of the patient organisation CMTC-OVM. The purpose of this document is primarily to provide an overview of the activities carried out in 2023.

**1.2 Foreword**

The patient organisation was officially established on 22 January 1997, by notary 'Van Helden' in Amsterdam, and subsequently registered with the Chamber of Commerce in Amersfoort. The purpose of the organisation, which is stated in the statutes, is expressed in the text below.

The mission is:

**Promoting the well-being of people suffering from vascular malformations such as CMTC ('Van Lohuizen syndrome'), in particular its own members, and promoting and developing activities that can promote this well-being. The promotion of (scientific) research with regard to vascular malformations such as CMTC, the causes and treatment thereof, and everything related to it in the broadest sense of the word.**

It is called CMTC-OVM, which stands for: Cutis Marmorata Telangiectatica Congenita and Other Vascular Malformations.

The logo is:

**1.3 Board**

As of 31 December 2023, the board is composed as followed:
Mr Lex van der Heijden, president;
Mrs Anja Fluijt, secretary;
Mrs Alexandra Haan, treasurer;
Mr Laurens Rorive, board member.

**1.4 Advisors**

Our advisors in 2023 are:
Mrs Prof. Dr Laurence Boon (Belgium)
Mr Dr Andrea Diociaiuti (Italy)
Mr Dr Kakha Bregvadze (Georgia)
Mrs Prof. Dr Chantal van der Horst (the Netherlands)
Mr Dr Patrick Kemperman (the Netherlands)
Mrs Dr Elyse Verboom (the Netherlands)
Mrs Dr Margaret Lee (USA)
Mrs Dr Christianne van Nieuwenhoven (the Netherlands)
Mrs Dr Charlène Oduber (Aruba)
Mrs Prof. Dr Tinatin Tkemaladze (Georgia)
Mrs Prof. Dr Suzanne Pasmans (the Netherlands)
Mrs Dr Beth Drolet (USA)
Mr Dr Millan Patel (Canada)
Mr Prof. Dr Maurice van Steensel (Singapore)
Mr Prof. Dr Peter Steijlen (the Netherlands)
Mr Prof. Dr Miikka Vikkula (Belgium)
Mrs Dr Maaike Vreeburg (the Netherlands)

More details about our medical advisors can be found on our website.

**1.5 Ambassadors**

At the end of 2023, we had three ambassadors. They are Prof. Dr Jan Peter Balkenende (former prime minister of the Netherlands), Dr Steve Groft (former director of rare diseases within the American National Institute of Health), and Eden Quine-Taylor (United Kingdom).

More details about our ambassadors can be found on our website.

**1.6 Volunteers**

The organisation is entirely run by volunteers, including the board. In addition to the board, various volunteers are active with different activities. For example, translation work and social media. Besides the board, as of 31 December 2023, approximately 50 volunteers were actively engaged worldwide, particularly in advocacy, translation work, membership/donor recruitment, auditing committee, complaints committee, and during member meetings. We also include our medical advisors and ambassadors in this volunteer count.

# 2 ACTIVITIES 2023

Thanks in particular to the subsidy from the Ministry of Health, Welfare and Sport, we were able to carry out a large number of activities in 2023.

The most important activities that we carried out in 2023 are:

1. **Members' conference**
2. **Family Day**
3. **Spring meeting**
4. **Brochure Parents Support Guide**
5. **Teachers Brochure**
6. **Advisors**
7. **Blogs**
8. **ERNs and ePAGs**
9. **Websites**
10. **External (online) conferences**
11. **Genetic research**
12. **The role of patient organisations in healthcare**
13. **Collaboration with (non-profit patient) associations**
14. **Rare Disease Day**
15. **Video material**
16. **Patient advocacy training**
17. **Newsletter**
18. **Fundraising**
19. **Certifications**
20. **Marketing**

### 2.1 Members' Conference

The worldwide members' conference started on Friday 27 October, and ended on Sunday after lunch.
What made this members' conference so unique, is that a few members from different countries had already arrived on Wednesday the 25th of October, so they could attend our unique patient advocacy training.

Around 65 people participated in our conference (some joined us via online streaming). Participants came from Belgium, Canada, Germany, the United Kingdom, Japan/Singapore, the Netherlands, Slovakia, the United States of America, and South Africa.

Reports and videos are available on our website.

### 2.2 Family Day

On Saturday 1 July, participants (86 from different countries) met at 9 a.m. at the Efteling. In the morning it was cloudy with a light drizzle. Because of this it was much calmer in the park and waiting times were quite short. In the afternoon the sky cleared up. After the meetup, there was a communal lunch around 1 p.m. After lunch, the mothers of children with a condition gathered again to catch up. In the late afternoon, we organised a joint snack moment that was well received. We specifically choose to plan the Family Day in July, because in the summer, the Efteling is open until 10 p.m., which means we have 12 hours to enjoy all the attractions!

### 2.3 Spring meeting

In 2023 we organised a spring meeting for the first time. We had chosen Bird Park Avifauna for this occasion. Unfortunately, it did not turn out the be a success. The number of participants was lower than expected, with several families cancelling last minute, mainly due to illness.

### 2.4 Brochure Parents Support Guide

In collaboration with the organisation Naevus Global, we have developed a series of disease independent brochures to support parents of children in different age groups (0-4 years old, 5-11 years old and 12-17 years old).

In 2022, we had a stand at the ISSVA conference in Canada. An American doctor from the National Institute of Health thought our Parents Support Guide series was spot on. However, according to her, one category was missing: the unborn child. In 2023, we started developing this new brochure in collaboration with a number of doctors from the U.S. National Institute of Health and the University of Philadelphia. It was published in multiple languages. Of course, all of these brochures are available in multiple languages, and can be downloaded from our website.

### 2.5 Teachers Brochure

School plays an important role in people's lives, because experiences at school can affect someone for the rest of their life. Due to our members being spread across the globe, we have accumulated a wealth of knowledge and experience over the years. How did they actually handle being 'different' at school? Were they bullied, and if so, how did they not let it affect them? With the help of this brochure, we provide support to primary school teachers who have or will have a student with a vascular malformation in their class. This brochure is designed for general education. This means that it is not primarily intended for special education, such as schools for children with behavioural problems. We would, however, like to make a small note: some parts of this brochure may still be applicable to special education. This brochure distinguishes between both the lower and upper grades in primary school (for example, between toddlers and year 6 students).

### 2.6 Advisors

We have several advisors from different countries in our team, for example medical specialists, genetic counsellors and mental health professionals. After all, a human being is so much more than just a body (holistic approach).
Sometimes, a specialist in our team quits their job (in most cases because they're retiring), but luckily, new people join our team very often.

### 2.7 Blogs

People with a condition really appreciate hearing or reading about other people's stories. Especially parents of young children find these very helpful. For the patients, it's the acknowledgement and recognition that matter. They finally find someone who understands them and knows what they are struggling with (very often for years on end). In December 2022, Katie Allen from Canada posted the first blog. She wrote a blogpost every month in 2023.

### 2.8 ERNs and ePAGs

We actively participate in the European Reference Networks and the European Patient Advocacy Groups for people with skin conditions (SKIN) and people with vascular malformation (VASCERN). In 2023, a new working party was established that is cross-cutting and focused on the field of psychology. We also take part in this working party that consists of doctors, psychologists, and patient organisations.

### 2.9 Websites

Not only do we have our main CMTC-OVM website, we also have a website for young adults, and a website to train patient advocates. Our main CMTC-OVM website is the largest website, which is updated weekly. This website offers, among other things, an enormous amount of information in multiple languages, but also the possibility to get in contact with other members through a secured online community.
In 2023 we began using artificial intelligence on our website. An example of this is the narration of parts of our brochures. The individual reading the text is a 'virtual' person.
The website for young adults (15-30) is meant as a way to provide information about vascular malformations in an understandable way and a tone that speaks to them. Additionally, they are able to contact each other through a safe and private online platform. Now, it's time to add the content for this demographic.

### 2.10 External (online) conferences

Due to COVID-19, all conferences were held online. In 2022, a part of the conferences were held in person again. Because hosting online conferences (or webinars) is relatively easy. A lot of additional conferences were organised from several time zones. We had to make some choices in this regard as well. For example, we participated in many different (international) conferences. The reports of these conferences are available on our website. President Lex van der Heijden was invited to a massive EADV conference (nearly 16.000 people present) in Berlin, to give a presentation in a parallel session, together with a doctor. We, as an organisation, also had a stand at this conference.

### 2.11 Genetic research

Most of the genetic research into CMTC is carried out in Belgium. Unfortunately, most of it is progressing very slowly, because it is still difficult to find enough patients with a 'classic type' of CMTC who also want to have a biopsy (piece of skin) taken. Although a mutation in the GNA11 gene is associated with CMTC in some cases, this is not the case for all patients. It is unknown whether this is due to the mutation being difficult to detect, because there is not much mutation to be found, or because of the mutation being in another gene. More information is available on our website.

### 2.12 The role of patient organisations in healthcare

Patient organisations are becoming increasingly important in patient care and the care for the patient's family. Fortunately, this is not only noticed by all those involved, but patient organisations are also increasingly involved in (medical) care. In the past, it was mainly the patient and their doctor who were involved. The doctor would primarily focus on the medical aspects. However, not only the medical aspects of living with a rare disease are important, some other aspects are as well. The disease often affects how the patient feels about themselves and their appearance. How do friends react when they hear about the disease and how does the patient deal with it at school on a cognitive (learning performance), physical (sports) and social (belonging to a group) level? What impact does it have on the parents and siblings?

In the cloverleaf model on our website, you can see all the parties involved in health care. More information is available on our website.

### 2.13 Collaboration with (non-profit patient) organisations

In 2023, we have entered partnerships with a number of umbrella organisations that deal with rare diseases in different countries. In 2024, we will start even more partnerships.
An up-to-date list of all the organisations we work with is available on our website.

### 2.14 Rare Disease Day

In 2023, we celebrated Rare Disease Day in Amsterdam.
You can find a report on this day on our website.

### 2.15 Video material

The amount of videos we make is increasing tremendously. At the end of 2022, we are at more than 200 videos. Some of them are publicly available, and some of them are for members only. During our member conference in 2023, we recorded a series of interviews with patients, patient's parents, and doctors. These will be available in 2024 with subtitles in multiple languages. We also have our own YouTube channel: https://www.youtube.com/channel/UCh6lHgOkcmkY9o6xJXs6lDQ

### 2.16 Patient advocacy

The biggest problem patients and the parents of our younger patients (our target audiences) run into is getting the proper medical diagnosis. This is, in fact, the case with all rare diseases. Moreover, getting in contact with other patients with similar problems is even more difficult when you do not have a diagnosis yet. Until then, living with this uncertainty is a big burden on everyone involved. That is why we use 'Patient Advocates' (PAs) in countries in which patients with CMTC and other vascular malformations live. A Patient Advocate is someone with experience about the disease (e.g. a patient or a close family member) who knows the language and culture of a particular country. A PA also knows all about local health care services and knows which doctors have sufficient knowledge of or experience with vascular malformations. This is necessary, for example, in order to get the proper diagnosis. Additionally, a PA is responsible for various tasks such as keeping and maintaining contact with fellow patients and sharing information about the disease on the internet and local social media channels. In 2020, we started training PAs as a project. Its main purpose was training PAs in the Netherlands and developing an eLearning module. This way, new PAs can access the training online everywhere and at any time. Due to COVID-19, this project has been delayed. Eventually, it was completed at the end of 2022. In 2023, we were able to carry out follow-up projects where PAs from 7 countries (Canada, Germany, England, Japan/Singapore, Slovakia, USA, and South Africa) came to the Netherlands at our expense. This training was part of our global conference in the Netherlands.

### 2.17 Newsletter

In 2023, our newsletter was published three times in both Dutch and English. You can find an archive of these newsletters on our website.

### 2.18 Fundraising

In 2023, we did some successful fundraising ourselves. In addition to the institutional subsidy from the Ministry of Health, Welfare and Sport, we have also received a project subsidy for the implementation of our PA trainings programme project.

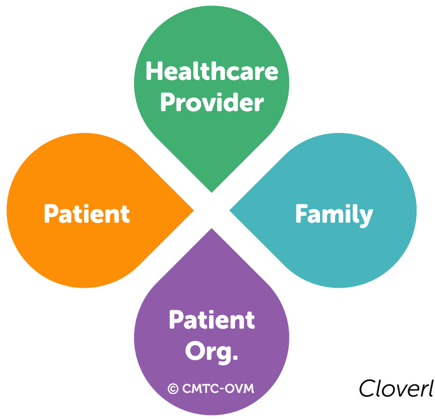
### 2.19 Certifications

We have various certification marks:

**ANBI (Dutch Tax Administration);**
**CBF (The Dutch Fundraising Regulator);**
**NORD (USA, Platinum status).**

### 2.20 Marketing

Marketing, in this context, encompasses promoting our organisation and sharing information about vascular malformations with the world. Our goal is to reach patients with vascular malformations, their families, healthcare providers and benefactors/sponsors. Moreover, we want to improve the awareness of the general public. We want them to know what kind of vascular malformations are and what exactly the patients are suffering from in their daily lives and in the long term. We use all kinds of social media platforms, such as Facebook, Instagram, Twitter, LinkedIn and YouTube. We also run campaigns via social media platforms like Google AdGrants, Facebook, and Instagram.



*Cloverleaf model*

# 3 FINANCIAL OVERVIEW

## 3.1 Introduction

Again this year we have been able to develop many activities in diverse areas and to further strengthen our position. Below is an overview of the various main items (expenditure and income).
The main items largely correspond to the structure which the Ministry of Health, Wellness and Sport. uses, namely:

The item ‘Backoffice’ is responsible for executing the jobs that aren’t part of our core tasks (the first three items on the list), like hosting our website, maintaining our social media platforms and creating graphic designs.

We have to fund the item ‘Enabling activities’ ourselves. This consists of the travelling expenses from the board of directors, bank charges and training for our volunteers.

1. Fellow patients;
2. Information provision;
3. Patient advocacy;
4. Backoffice.

### 3.2 Overview of Expenditure

| ACTIVITY | EXPENDITURE 2023 (€) | EXPENDITURE 2022 (€) |
|---|---|---|
| 1. FELLOW PATIENTS | 27.649 | 26.607 |
| 2. PROVISION OF INFORMATION | 11.300 | 11.382 |
| 3. ENABLING ACTIVITIES | 711 | 932 |
| 4. PATIENT ADVOCACY | 16.652 | 19.305 |
| 5. PROJECTS | 20.597 | 11.176 |
| 6. BACKOFFICE | 17.232 | 11.911 |
| TOTAL | 94.141 | 81.853 |

### 3.3 Receipts

| SOURCE | INCOME 2023 (€) | INCOME 2022(€) |
|---|---|---|
| MINISTRY VWS AND PROJECTS | 75.485 | 61.955 |
| CONTRIBUTIONS | 4.381 | 3.847 |
| DONATIONS/GIFTS/OTHER BUSINESS | 8.315 | 1.371 |
| TOTAL | 88.181 | 67.173 |

### 3.4 Utilisation

| | 2023 | 2022 |
|---|---|---|
| SPENDING PERCENTAGE OF EXPENSES % | 80,94 | 84,21 |
| BENEFITS OF SPENDING (%) | 86,41 | 78,51 |

# 4 FORWARD LOOKING

The world is changing rapidly and COVID-19 has played a crucial role in this. In the past, patients and doctors would rarely speak to each other via a video connection. In most cases the patient had to travel to the doctor. In a very short time, due to COVID-19, telehealth has become the norm. We expect telehealth services to become even more important in the future. From what we have seen and experienced, more conferences will be held online. In 2020, as we've all experienced during COVID-19, all of a sudden, conferences were held online. It is obvious that online conferences have many advantages. For example, they are easy to organise and inexpensive. Furthermore, no extra costs are made for travelling time and travelling expenses. However, one thing in particular is missing: human contact, being able to look each other in the eye.

In the case of international conferences, time zones can be a problem too, like when someone from Europe wants to attend an online conference held in Asia or in the USA. In this case, a hybrid conference can provide a solution (this means that the conference is held both in person and online). We do not expect any change in the fact that not many people want to become a member of an organisation. After all, it is easy to get in contact with other patients or families through social media platforms, such as Facebook (groups). In 2023, the Dutch ministry of Health, Welfare and Sports has set up a new subsidy policy framework, that takes effect at 1 January 2024. The subsidy was raised from 55,000 euros to 75,000 euros.
In the Netherlands, using experts in all kinds of committees is considered necessary and valuable (based on the motto "Nothing About Us Without Us, the key principle in the field of disability rights). Because of this, experts are valued more and more every day and thus receive more financial support. Reaching patients between 15-25 years old has turned out to be difficult. We want them to talk about their problems and to tell us what they need as well. That is why we have decided to collaborate with youth organisations, in particular with organisations that focus on young people with a disorder. The number of international contacts will also continue to increase, as will the number of foreign members. By using the internet, we want to strengthen our network worldwide and act as a key figure between doctors and between patients and doctors. Contacts via international umbrella organisations, such as Eurordis and NORD, remain very important. They provide us with access and opportunities that would not have been possible for a small organisation if we wanted to achieve this on our own. Two of the key elements are collaborating and sharing knowledge and experience. These are also important in order to improve the lives of patients and their loved ones. Currently, around 7,000 rare diseases have been identified and the number of patients with a rare disease is very low. This means that it not only takes many years before a patient organisation receives some recognition, but also that this must be done continuously by using marketing. This not only requires additional efforts in terms of time, but also financially. In 2023 we began using artificial intelligence on our website. In 2024, we plan to further expand this within our organisation.

1. **Organising a hybrid international members' conference (both online and in-person in the Netherlands). If the financing process of this project is completed, we hope to be able to organise this in addition to the Patient Advocate training (2024).**

2. **Organising a family weekend in the Netherlands. Thanks to the extra subsidy, this will be possible. This also aligns with the need of our members to see each other more often.**

3. **Organising an informal international Family Day in the Netherlands, so that the patients can just have fun with their friends and family and to give them the opportunity to get to know other patients. The goal is to do things together with other patients and their immediate family. This also gives them an opportunity to share experiences and knowledge with each other.**

4. **Reaching the target audience with the age of 15-25, in cooperation with for example JongPIT!**

5. **Organising public webinars.**

6. **Expanding our new website with both higher functionality and more content. Creating content together with the target audience (young people). Further utilisation of artificial intelligence.**

7. **In 2022, we started a blog on our website. In 2024, we plan to recruit more bloggers with various disorders.**

8. **Maintaining and expanding our contacts and working together with other patient associations, both in the Netherlands and abroad.**

9. **Maintaining and expanding our contacts with medical experts (for example dermatologists), both in the Netherlands and abroad.**

10. **Researching vascular malformations, such as CMTC, in particular genetic research into DNA material of patients. However, it seems very hard to find enough patients who want to have a biopsy taken. Moreover, the administrative processing is very complex and time-consuming due to privacy legislation. This research is carried out at the De Duve Institute in Brussels (Belgium) by one of our advisors (Prof. Dr. Miikka Vikkula).**

11. **Sustainability in the healthcare sector is extremely important to us. This means that, if you are getting diagnosed abroad you need to be able to receive treatment in your own country. This should happen after getting medical advice and after consultation with the virtual advisory panel that consists of medical specialists abroad. In the European Union, the European Reference Networks (ERN) applies. The goal is to have advisory panels on diseases that are covered by ERNs in each country. Due to the fact that not all countries in the EU have advisory panels patients sometimes have to go to an advisory panel abroad (cross-border healthcare).**

12. **Our Patient Advocates project turned out to be one of a kind. Our second PA project is finished and we plan to raise funds for a follow-up project (second phase).**

13. **Now that the first PAs have been trained, we are aiming to organise local (country specific) events. We have set aside a budget for this.**

14. **Expanding our social media campaigns and taking into account the fact that search strategies are constantly changing. We run our campaigns via Google AdGrants, and Facebook and Instagram advertisements.**

15. **Increasing our activities on Facebook, Instagram, YouTube, Twitter and LinkedIn. This is part of our PA concept. Example: We publish something on our international Facebook page. Our PAs then repost this in their own language on the Facebook pages exclusively for their country, and in some country specific Facebook groups.**

16. **Raising funds in order to organise and develop additional activities (especially projects) and to be able to become less financially dependent on the Dutch government.**

17. **Promoting our organisation and recruiting members and contributors by using social media. We use Google AdWords, and Facebook and Instagram campaigns to achieve this.**

18. **Active participation in the European Reference Networks and European Patient Advocacy Groups (ERNs and ePAGs).**

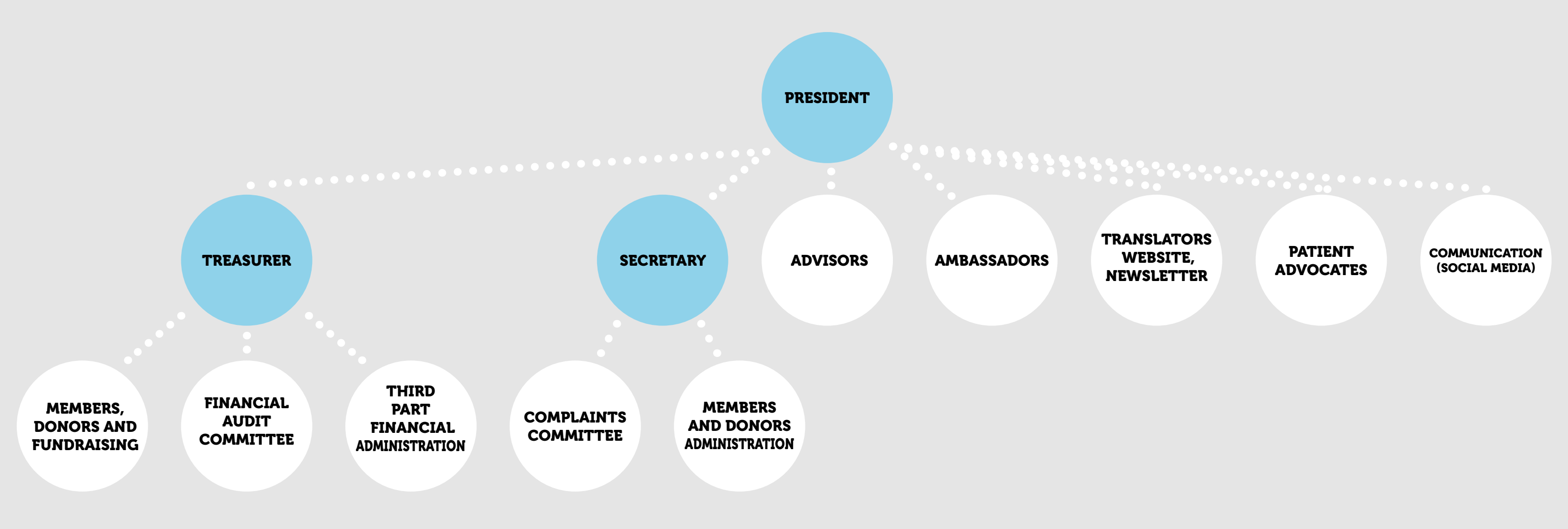
19. **Publishing a newsletter. The idea is to actively cover news and refer readers to our website for more information.**

# 5 AVAILABILITY OF PEOPLE AND RESOURCES

The amount of available people is quite limited in a small organisation. However, the amount of work is not proportional to the size of our organisation, which means that a considerable amount of work needs to be done. The board of directors has been expanded and consists of four members as of 2022. Our organisation has around 50 volunteers, who live all over the world. In 2024, we plan to expand our board of directors.

A lot of work, for example, has been done through the use of extra volunteers for translation work and other various activities. Members even sign up spontaneously to perform activities. The budget for 2024 consists of the main items: contact with fellow sufferers, provision of information, advocacy, back office and enabling activities.

We are a transparent organisation so this budget is also published on our website.



| ACIVITIES (EXPENDITURE) | BUDGET 2024 (€) |
|---|---|
| WITH FELLOW SUFFERERS | 44.200 |
| PROVISION OF INFORMATION | 9.800 |
| ADVOCACY | 24.300 |
| ENABLING ACTIVITIES | 950 |
| BACKOFFICE | 11.000 |
| **TOTAL** | **90.250**<br>(ADDITIONAL FUNDS) |

| INCOME SOURCES | BUDGETED 2024 (€) |
|---|---|
| MINISTRY VWS | 75.000 |
| SUBSCRIPTIONS (MEMBERS, DONATIONS AND SPONSORS) | 5.750 |
| OTHER | 800 |
| **TOTAL** | **81.550** |

We carry out extra activities on a project basis, which are funded separately.

# 6 CMTC-OVM AND THE ENVIRONMENT

Just as with other companies, our activities can have a negative environmental impact. We have taken the following measures to limit any negative environmental effects:

1. **Newsletters etc. are made available via the website.**
2. **Double sided paper printing happens as much as possible.**
3. **We carpool whenever we can. However, if possible, we use public transport.**
4. **Computers are only switched on if they are actually being used.**
5. **If possible, a meeting is held online or by telephone (e.g. via ZOOM). We do this, for example, with our board meetings.**
6. **Email is preferred to physical mail.**
7. **Empty inkjet cartridges are collected and returned to the designated collection points.**
8. **Paper, plastic and chemical waste are separated from the other waste and are disposed of separately.**
9. **Materials are recycled and reused as much as possible.**

# 7 APPENDIX A TERMS AND ABBREVIATIONS

| **Term/abbreviation** | **Explanation** |
|---|---|
| **ANBI** | **Algemeen Nut Beogende Instelling (Public Benefit Organisation).** |
| **CBF** | **Centraal Bureau Fondsenwerving (The Netherlands Fundraising Regulator).** |
| **CMTC-OVM** | **Our organisation.** |
| **Eurordis** | **Europese organisatie voor zeldzame ziekten (European Organisation for Rare Diseases).** |
| **Fonds PGO** | **Subsidie vertrekker vanuit Nederlandse Overheid (Subsidy provider by the Dutch government) for patients, disabled people and elderly.** |
| **GDPR** | **General Data Protection Regulation.** |
| **NORD** | **National Organization for Rare Disorders (USA).** |
| **VSOP** | **Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (Dutch Patient Alliance for Rare and Genetic Diseases).** |

ANNUAL REPORT 2023

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL/EN